

AUTISMS

THE IRONY OF “BLACK AND WHITE THINKING” ABOUT A COMPLEX ARRAY OF DISORDERS

BEYOND CATEGORICAL ASSESSMENT

Dan Shapiro, M.D.
Developmental-Behavioral Pediatrician
Rockville, MD
drdanshapiro@gmail.com

Overview

- Categorical assessment: DSM5
- Beyond categorical assessment
 - Etiologic assessment
 - Functional assessment
 - Transactional assessment
- Repercussions for management

Three Purposes of Assessment

1. Categorical diagnosis
2. Etiologic evaluation
3. Functional assessment

Putting it all together:

4. Transactional (multi-dimensional) assessment

Categorical Diagnosis

- Establishes the diagnosis of an Autism Spectrum Disorder, to:
 - Gain eligibility for special services
 - Justify insurance reimbursement
 - Facilitate communication
 - Demystify developmental difference
- Based on DSM
 - ADOS, ADI, etc.

DSM5 criteria for ASDs

- Must meet criteria 1, 2, and 3:
- **1. Clinically significant, persistent deficits in social communication and interactions, as manifest by all of the following:**
 - a. Marked deficits in nonverbal and verbal communication used for social interaction:
 - b. Lack of social reciprocity;
 - c. Failure to develop and maintain peer relationships appropriate to developmental level
- **2. Restricted, repetitive patterns of behavior, interests, and activities, as manifested by at least TWO of the following:**
 - a. Stereotyped motor or verbal behaviors, or unusual sensory behaviors
 - b. Excessive adherence to routines and ritualized patterns of behavior
 - c. Restricted, fixated interests
- **3. Symptoms must be present in early childhood (but may not become fully manifest until social demands exceed limited capacities)**

Caution: screening vs. diagnosis

- ***Nonspecific Level I Screening:*** Identifies children “at risk” for any disability from the general population
- ***Autism-specific Level I Screening:*** Identifies children specifically “at risk” for Autism from the general population
- ***Level II screening/diagnosis:*** Differentiates children with autism from those with other developmental disorders

Differential diagnosis and coexisting conditions

- Difficult temperament/ behavioral style
- ADHD
- Executive Dysfunctions (“ISIS”)
- Language-based Learning Disabilities
 - Formal: phonology, semantics/ vocabulary, syntax, language comprehension and expression
 - Pragmatic, Non-Verbal, Social (non-literal, interpersonal)
- Intellectual Disability (“MR”)

Differential diagnosis and coexisting conditions (continued)

- Mood disorders: anxiety, OCD, depression, bipolar, severe emotional dysregulation
- Thought disorders (schizophrenia)
- Uneven sensory profile
- Fine and gross motor disorders (CP, apraxias)
- Movement disorders (chronic tics, Tourette's)
- Sleep disorders

Differential diagnosis and coexisting conditions (continued)

- Severe environmental disadvantage
 - Neglect
 - Abuse
 - Deprivation or adversity
 - Lack of positive social role models and social teaching
- Parent psychopathology
- Family system pathology

Etiologic Evaluation

- Identifies specific underlying neurobiological, genetic, metabolic or environmental causes, to:
 - Subtype Autism Spectrum Disorders
 - Promote research on prevention and management
 - Possibly inform families regarding prognosis and heritability

Etiologic Evaluation

- Fragile X Syndrome
- Tuberous Sclerosis
- Angelman Syndrome
- Prader-Willi Syndrome
- Williams Syndrome
- Down Syndrome
- Smith-McGuiness Syndrome
- Velocardiofacial Syndrome (DiGeorge/ 22q11 deletion)
- Duplication of 15 q 11-13
- Metabolic disorders
- Mitochondrial disorders
- Seizure disorders (Landau-Kleffner Syndrome)
- Fetal Alcohol Syndrome
- And the list keeps growing

Etiologic Evaluation (continued)

- Hearing and vision assessment for every child
- Controversy: Genetic investigation for all? Or *only if* global developmental delay/intellectual deficiency/specific evidence of a syndrome?
 - Microarray Comparative Genomic Hybridization (mCGH)
 - DNA for fragile X
 - More specific studies *only* as indicated
- EEG, metabolic studies, fMRI *only* as indicated

Functional Assessment

- Determines overall *and* domain-specific functional levels, to:
 - Specify disparities between potential and real-life capacities
 - Establish baseline against which progress can be measured
 - Guide individualized management

Functional Assessment

- ***Cognitive/developmental potential***
 - Mullen
 - Bayley
 - Capute Scales
 - WPPSI-III
 - WISC-IV
 - Leiter-R
 - Differential Abilities Scales,
 - etc.

Functional Assessment

- *Achievement*

- Assessment of Basic Language and Learning Skills
- VB-MAPP
- Woodcock-Johnson
- Vineland Adaptive Behavior Skills
- Adaptive Behavior Assessment System
- etc.

Functional Assessment (continued)

- Comprehensive speech-language assessment includes *formal* aspects of linguistic skills
 - *Phonology*
 - *Vocabulary*
 - *Language comprehension and expression*
 - *Syntax*
- But...

Functional Assessment (continued)

- Comprehensive speech-language assessment should also include *informal* aspects:
 - *prosody* (volume, pitch, rate, stress, phrasing)
 - *pragmatics* (social context, conversational rules, turn-taking)
 - *metalinguistics/ non-literal speech* (metaphor, irony, sarcasm, humor)
 - *language of mental states* (intentions, motivation, beliefs, thoughts, feelings)
 - *narrative skills*
 - *early social skills* (communicative intent, joint attention, symbolic behaviors)

Functional Assessment (continued)

- Occupational/Sensorimotor assessment
- Functional Behavioral Assessment (FBA)
- Assessment of family functioning and environmental stresses
- Strengths and interests

Transactional assessment

Mel Levine: "Dysfunction at the junction of the functions"

- *Autism in DSM5 does require individual etiologic and functional specifiers*
 - severity
 - current language functioning
 - intellectual level/disability
 - known genetic disorders
 - epilepsy (15-40%)
- *4 types of "inattention"*
 - ADHD (distractible, impulsive)
 - Autistic (perseveration, difficulty shifting)
 - LD/ DD (secondary loss of attention due to task difficulty)
 - Anxiety
- *FBA and Family Systems Theory*
 - Closed/ liner vs. open/ intergenerational

Transactional assessment

Heraclitus: *“No man ever steps in the same river twice, for it's not the same river and he's not the same man.”*

Over time...

- Changing profile
 - mood disorder
 - growing off the curve
- Changing social-cultural milieu
 - school, family
- Changing medical / economic culture
 - DSM IV to DSM5
 - International, intra-national differences

Assessment reminders

- Nothing is more important than good ol' history, physical exam and observation.
- Autism assessment must include observation of peer interaction.
- Assessment must take place across settings, across people, and over time.

MANAGEMENT GOAL

- “To improve the overall functional status of the child by promoting the development of communication, social, adaptive, behavioral and academic skills; lessening maladaptive and repetitive behaviors; and helping the family manage the stress associated with raising a child with autism.”
 - *National Research Council, Educating Children with Autism, National Academy of Sciences (2001)*
 - *Also see National Standards Project, Phase 2, 2015 (www.nationalautismcenter.org)*

Principles of Intervention

- Begin *early*
- Continue across the *lifespan*
- Insure sufficient *intensity*
- Provide sufficient *structure*
- *Individualize* plan based on functional assessment
- Remediate *and* accommodate
- Address weaknesses *and* strengths

More Principles of Intervention

- Be *comprehensive*
- Use multi-disciplinary *team* w/ case manager
- *Empower* the child and family
- Promote *inclusion/mainstreaming*
- *Generalize* and maintain learned skills
- *Measure* baseline and progress towards goals
- *Modify* the plan if insufficient progress
- “Keep it *real-life*” (Natural Environment Teaching)

The Great Debate: Which Model?

- Applied Behavior Analysis/ Discrete Trial Training (Lovaas)
- Applied Verbal Behavior (Skinner/ Carbone)
- DIR/ “floor-time” (Greenspan)
- Relationship Development Intervention (Gutstein)
- Pivotal Response Training (Koegel(s))
- TEACCH (Chapel Hill, NC)
- Hanen Program
- The Early Start Denver Model (Rogers)
- Etc.

“If you only have a hammer, all the world’s a nail.”

Non-evidence-based Treatments

- Nutritional supplements/ Elimination diets (CF/GF)
- Immunoglobulin therapy/ Steroid therapy
- Secretin/ Chelation
- Auditory integration training
- Developmental optometric training
- Interactive metronome/ Facilitated communication
- Sensory integration therapy
- Chiropractics/ acupuncture/ hyperbaric oxygen

Conventional Management

- Family/ parent/ sibling support
- Speech-language therapy
- Behavior management
- Educational care
- Social skills
- Individual psychotherapy
- Occupational therapy/ Physical therapy
- Medication management
- Transition planning
- Nurture strengths and interests

Family/ parent/ sib support

- Education, counseling, training, coaching
- Disclosure/ dealing with others
- Genetics consultation
- Support groups
- Psychotherapy/psychiatric care as indicated

Speech-Language Therapy

- Top priority: ensure a system of communication, usually emphasizing visuals
 - Visual schedules, “if-then” boards
 - Picture Exchange Communication System (PECS)
 - Sign Language
 - Augmentative and Alternative Communication (AAC) technology (Proloquo-2-Go, Tango, etc.)
 - Video/ computer-based learning

Behavior Management

- Neurodevelopmental approach
- Behavioral approach

Behavior Management (continued)

- Neurodevelopmental approach: What is it about the *child's profile* (specific skill deficits) that explains the behavior?
 - Language deficits
 - Executive skills deficits
 - Social-emotional skills deficits
 - Motor deficits
 - Etc.
- Accommodate and/ or remediate

Behavior Management (continued)

- Functional Behavioral Analysis approach: What is it about the *situation* that explains the behavior?
 - Positive reinforcement (reward)
 - Social (attention, access to tangible materials)
 - Automatic (sensory stimulation)
 - Negative reinforcement (relief)
 - Social (escape from task demands)
 - Automatic (pain attenuation)
- Fix the situation

Educational Care

- Comprehensive assessment leads to...
- Comprehensive IEP in “least restrictive environment”
- Includes communication, social, emotional, and adaptive life skills goals – not just academics!
- Leave No Child - with Autism - Behind!
 - Under age 3, through State Early Intervention System
 - Over age 3, through local school system

Social Choreography and Skill Building

- Developmentally appropriate opportunities for social success; facilitated, coached
- Training in social skills/ social thinking
 - Individual or group
 - Social Stories (Carol Gray)
 - Interactive DVD
 - Indirect learning: pets, books, etc.
 - Classroom/ playground
 - Peer-mediation/ social engineering

Individual Psychotherapy

- Child-led: DIR/ “floor time”/ play therapy
- Therapist-led: Cognitive-behavioral therapy

OT/ PT

- Specific adaptive skills
- Specific measurable goals
- Examples:
 - Eating
 - Toileting
 - Dressing
 - Writing/ keyboarding
 - Participation in peer play/ games
 - Executive skills: time management, transitions
- Assistive/ Augmentative/ Adaptive Technologies (computers, blue-tooth, i-pad, MP3, DVD, etc.)

Medication Management

- Can not treat core deficits of autism
- Can treat symptoms that cause distress or impair availability for learning and socializing
- Begin only on a trial basis and with specific outcome measures
- “Start low and go slow”
- Continue only if significant improvement and no significant side effects
- 25 -60% of children with ASD take psych meds; rates and number of meds increase with age

Potential Medication Targets

- Anxiety (SSRIs, buspirone, propranolol)
- Depression or OCD (SSRIs)
- ADHD (stimulants, guanfacine, atomoxetine)
- Irritability/ aggression/ self-injury (neuroleptics)
- Mood instability (neuroleptics, mood stabilizers)
- Sleep problems (melatonin, Benadryl, clonidine, Remeron, Trazadone)
- Seizures (anticonvulsants)
- Specific medical conditions (allergy, GE reflux)

Transition Planning

- Disclosure and self-advocacy
- Life skills training
- Sex education
- Vocational planning and training
- College for Asperger-type ASD
- Life-span planning
- Group homes
- Financial planning

Nurture strengths and interests

- Leisure activities
 - Sports
 - Drama
 - Music
 - Art
 - Technology
- Special interests/ relative strengths are the keys to future success

References and Resources

- Temple Grandin, Thinking in Pictures
- Mesibov, et. al The TEACCH Approach to Autism Spectrum Disorders
- Carol Gray, Social Stories
- Tony Attwood, The Complete Guide to Asperger Syndrome
- Tony Atwood, Mind Reading, The Interactive Guide to Emotions (Jessica Kingsley Publishers-DVD)
- Simon Baron-Cohen, The Essential Difference
- Lynn Koegel, Overcoming Autism
- Fred Volkmar et. al., Handbook of Autism and Pervasive Developmental Disorders
- Catherine Faherty, What Does It Mean To Me? (Future Horizons)
- Greenspan and Wieder, The Child with Social Needs, Engaging Autism
- Daniel Goleman, Social Intelligence
- Bryna Siegel, The World of the Autistic Child
- Bondy and Fost, A Picture's Worth, PECS and Other Visual Communication Strategies in Autism
- McClannahan and Krantz, Activity Schedules for Children with Autism
- National Research Council, Educating Children with Autism (2001), National Academy Press.
- Michael Power, Children with Autism: A Parent's Guide
- Daniel Tammet, Born on a Blue Day
- Roy Grinker, Unstrange Minds
- www.autism-society.org
- www.nas.org.uk
- www.asperger.asn.au
- Autism Speaks
- First Signs